

Interim Report
Develop a Community Involvement Strategy
Prepare to Implement a Cohort Study of Children's
Environmental Health

Prepared for:

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**Deliverable: Interim Report for Task 3,
Develop a Community Involvement Strategy**

**Prepare to Implement a Cohort Study of Children's
Environmental Health**

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1.0 Introduction

The National Children's Study (NCS) is an ambitious undertaking—a 20-year prospective cohort study that will investigate the relationships between a broad range of environmental factors and the health and well-being of children. Approximately 100,000 U.S. children will be followed from prenatal development through to adulthood. There are many factors that will help ensure a successful study, and key among them is the ability to recruit and retain participants for a long term follow-up. For the past four years, NCS planners have been examining the question of community involvement in light of approaches that would promote buy-in from the community and help to ensure high recruitment and retention rates among study participants. Issues surrounding the development of an effective community involvement approach include:

- defining the “community”
- identifying key community stakeholders and their roles
- community empowerment
- building on existing relationships with community-based organizations
- developing a consistent overall message about the study
- developing a community profile that can be used to tailor messages to specific groups and subgroups
- information dissemination among the community

The North Carolina Cohort Study (NC Cohort Study) will provide an opportunity to examine, and perhaps field test, the various methods by which communities can participate in and promote a study such as the NCS. This report has been prepared in response to Task 3 of the work assignment, *Prepare to Implement a Cohort Study of Children's Environmental Health*. The purpose of this task is to begin to create a community involvement strategy for the NC Cohort Study. While many of the details (e.g., selection of primary sampling units, length of follow-up) remain to be determined, this report will lay the groundwork from which community-specific strategies can be developed.

Because the success of the study will depend on the extent to which communities participate in the research, we begin by presenting the general principles of community-based research (CBR) to provide a framework for designing effective strategies. We proceed with a description of specific steps in garnering community involvement, and provide examples of different approaches to these steps. Various approaches are suggested, depending on the level and extent of community involvement desired. The community involvement strategy for an observational study will require a somewhat different approach than that typically undertaken for research that incorporates community-based intervention activities; our discussion will incorporate this perspective.

2.0 General Principles of Community Involvement

As described by Israel et al. (1998), community-based research in public health is a partnership approach to research, which equitably involves community members, community organization representatives, and researchers in all aspects of the research process to enhance understanding of a given phenomenon and to integrate the knowledge gained with action to improve the health and well-being of community members. This process, although labor and time intensive, can yield excellent results if approached using proven principles.

There are several major principles that lay the framework within which we will approach the community involvement process for the NC Cohort Study. These broad principles address many of the same issues that have been discussed among NCS planners and include: identifying and addressing the needs of the community, establishing trust among community members, and determining the level of community involvement and types of partnerships needed.

2.1 Identifying the Community and Community Stakeholders

As a first step in formulating a community involvement strategy, the community itself needs to be defined. For the NC Cohort Study, the selection of primary sampling units would guide the selection and definition of the communities they contain. The most successful community based research (CBR) has been that which invests the time to become acquainted with the community early on in the project, and establishes and maintains a presence in the community, whether directly or through community stakeholders and member partners. The extent to which a study is legitimized and supported within a community can be greatly enhanced by using this approach. Identifying key community representatives is also a critical step, and one which should be taken as early as the study design stage. While there are many organizations and groups from which to select community partners, the best choices are those that community members regard as adding value to their community. Once these groups are chosen, the next step is to identify individuals within these groups that have extensive experience working with the community, and to enlist their participation. These community stakeholders will be the basis for establishing the partnerships and trust needed for the study.

2.2 Building Collaborative Relationships

The importance of collaborative relationships and community empowerment in the success of CBR cannot be overemphasized. The establishment of collaborative relationships is affected not only by the extent to which researchers have become acquainted with the community and community stakeholders, but also by the researchers' ability to establish trust and know the needs and resources of a community. Building trusting relationships can help resolve hesitations of those communities which

historically have been rather distrustful of research and of researchers, whether due to real or perceived actions.

A guiding concept of effective CBR is community empowerment. Establishing a balanced relationship between the experts (researchers and policy makers) and the community in which the research is being conducted helps both parties to share some of the power and control they exert over their own areas of interest. This empowerment, especially on the part of the community, allows researchers to better understand the dynamics of the community and provides community stakeholders with the incentive to accept their roles and responsibility in making the research endeavor an effective and successful one.

The quality of a collaborative relationship can also be improved when researchers have a clear understanding of a community's needs and resources. By identifying resources available to the community and comparing them to its needs, an agreement can be reached regarding what roles each group can best play to achieve the common goals of the study. This process also allows researchers to evaluate the effectiveness of the study design in a community environment, and to identify topics of concern in a community that could be addressed by the study.

2.3 Principles of Partnerships

The topics described above refer to some of the initial and most important steps in involving a community in a research project. While the extent and nature of relationships can vary depending on the type of study and the community involved, the core guiding principles for sustaining working relationships between researchers and communities are essentially the same. As defined by one organization involved in community based research, these are (CCPH, 1997):

- Partners must agree on missions, goals, and outcomes.
- Partners should have mutual trust, respect, and commitment.
- Partnerships need to build on identified strengths and assets. Instead of approaching a community-based partnership solely by itemizing all of the problems that the community faces, the partners should also identify their strengths and assets.
- Good partnerships should have clear communication among partners and transparency in the decision-making process.
- Partnerships evolve using feedback to, among, and from all partners.
- Roles, norms, and processes for the partnerships should evolve from the input and agreement of all partners. Partnerships need a governance structure that establishes a common understanding of how to proceed.
- Successful partnerships have relationships with local leaders and funding agencies.

2.4 Levels of Community Involvement

Within the general principles of partnerships, there can be varying levels of community involvement as partners in CBR. Hatch et al. (1993) described four levels of community involvement, from the first level in which the community partners serve in an advisory capacity, to the fourth level in which the community actively participates in the research agenda. Each successive level reflects an increase in the level of community participation and control (i.e., empowerment), and a resultant decrease in the control held solely by the researcher. While level four represents the deepest level of community involvement, it also presents communication and trust challenges, as well as an opportunity for both community gatekeepers and researchers to work together to address these challenges and find a common ground to achieve the research goals.

3.0 Community Involvement Strategy for the NC Cohort

The general principles described above have been incorporated into the outline of steps necessary to finalize a community involvement strategy for the NC Cohort. While the exact number and nature of the communities will not be known until the sampling strategy is finalized, we expect that the sample will be drawn from a mix of urban and rural communities in North Carolina. The sampling strategy must also be finalized with respect to the inferential requirements of the demonstration cohort. If it is not necessary to make inferences to the state of North Carolina, then the number of primary sampling units (and possibly their geographic distribution) will be smaller. Geographic dispersion of the sample will impact some of the detailed decisions regarding the community involvement strategy, for example, communities located in different regions of the state may each require their own community involvement approaches.

Step 1: Finalize Sampling and Geographic Area Assumptions

RTI expects that the LCS planning team, composed of members from the U.S. EPA and other federal agencies, will make the final determination of the sampling strategy for the NC Cohort Study. Once the sampling design is finalized and carried out, we will be able to determine the specific communities whose involvement we seek. Additionally, we will be able to use data on urbanicity, ethnic, and sociodemographic characteristics to begin to refine the community involvement strategy to reflect the particular locations and subgroups selected.

Step 2: Determine Level of Community Involvement Sought by EPA

As described earlier in this report, there are varying levels and types of community involvement. Each level brings with it a corresponding degree of required planning and resources. Some strategies have obvious advantages over others, and some strategies work better with one community than with another. Because the NC Cohort Study will allow us to field test procedures in order to inform the full

NCS, we expect that the LCS planning team will provide guidance as to the level of community involvement sought as well as the options to be tested. RTI will use this feedback to further refine the strategy for community contacts and partnering efforts. We will work with the planning team to determine at what point to bring in the communities, identify the organizations and groups to contact, create appropriate messages to communicate to community members, and decide on the types and frequency of information to provide to communities as the study progresses.

Step 3: Identify Community Stakeholders

Once the specific communities have been defined, RTI will begin identifying appropriate community stakeholders. There are various options, or combinations of options, in which to accomplish this step. The first stage, however, should be a careful study of the communities and their composition, and the beginnings of an approach strategy. This includes gathering information about the ethnic and cultural makeup of the community, and trying to identify resources and needs. This is especially important in a study such as the NCS, which may have the opportunity to explore environmental justice and health disparities issues. The process will not only help in the initial formulation of involvement and communication strategies, but also in the identification of the organizations and groups that are active in and knowledgeable about the community.

RTI proposes to begin with a list of the North Carolina community organizations and leaders that provided us with letters of support for the LCS. *Exhibit 1* names some of these organizations. Based on our experience conducting other studies in the area, we could also recommend additional names of state and local health officials and other key organizations in the region, especially those that are already involved in collaborative research in the community. We will work with the LCS planning team to determine other related stakeholders that are representative of the communities chosen in the sample.

An additional approach to identifying key stakeholders might be to use RTI's internal geographic information system (GIS) services to identify community clinics or other relevant institutions that fall within the geographic sample areas. Depending on the extent to which these types of healthcare organizations are involved in the community, it would be helpful to enlist their support, especially if they are clinics that provide services to low-income and minority groups.

With the planning team's approval, RTI could expand on the lists of community organizations by using the "snowball technique." The snowball technique is a process in which the initial persons contacted generate suggestions for additional persons to contact. We believe this approach could be an efficient and cost-effective one, in part because we have already generated a starting list. This approach could also be used to learn more about the communities represented by persons and organizations

approached, while also enabling community stakeholders to become acquainted with and develop trust in the research team.

Exhibit 1. Organizations that support the Longitudinal Cohort Study

State and Local Offices

- Wake County Human Services
- North Carolina Department of Health and Human Services
- County of Durham Health Department
- Johnston County Public Health Department

Universities and Health Care Providers

- University of North Carolina at Chapel Hill
- Duke University Health System

Medical Societies and Associations

- American Lung Association of North Carolina
- North Carolina Hospital Association
- American Cancer Society, Southeast Division
- North Carolina Obstetrical and Gynecological Society
- North Carolina March of Dimes
- North Carolina Medical Society

Step 4: Revise and Finalize Community Involvement Strategy

Upon creating a list of potential community stakeholders and formulating an initial community involvement strategy, RTI will meet with the LCS planning team to review and revise these documents and procedures. Before moving forward with contacting community stakeholders and implementing the strategy, the planning team will need to approve the list of organizations and decide their level of involvement in the study. For example, some larger state-based organizations may be brought in at a cursory level to lend their overall support and help to legitimize the study among the community, while smaller local organizations and community groups could be asked to participate more actively in the refinement of the community involvement strategy.

We recognize that developing the community involvement strategy will be a dynamic process, involving continuous communication with the LCS planning team as well as revisions based on feedback from the community and lessons learned throughout the process. However, some initial decisions will need to be made in order to proceed with the initial approach. For example, we will need to formulate an overarching message or “mission statement” for the study, which can be revised and used to target specific communities or subgroups. As emphasized in the December 2002 Community Engagement Workshop, the message must clearly describe the study and what it can and cannot provide to the participants. It should emphasize the positive aspects of good health, while also recognizing disease and

other adverse outcomes that may be of concern in the community. It should be culturally sensitive and crafted to attract women of childbearing age from all segments of society.

Another critical decision is to what extent community members themselves will have an opportunity to be involved in the study. Some members of the NCS committees have advocated sharing leadership responsibilities among the community, suggesting the possibility of hiring key community members to help develop and implement aspects of community outreach and to act as the study “cheerleader” in order to gain participation among other members. Other suggestions have included the creation of community advisory boards with representation from the scientific and local communities; the roles and responsibilities of the community advisory boards might vary considerably.

Finally, we will need to explore the various communication channels to the community, as well as what types of information should be communicated. There will be venues and methods that are more effective in the initial community engagement and participant recruitment phase, and others that will be more appropriate for participant retention once the study is underway. Some examples of possible communication and outreach methods include media campaigns, health fairs, town hall meetings, and advertisements.

Step 5: Contact Community Stakeholders and Implement Strategy

As previously mentioned, establishing partnerships with community stakeholders will allow us to become acquainted with the community itself, and to establish a presence early enough to garner the support of the community for the study. A key aspect of communication with the gatekeepers and community leaders will be to identify common grounds of interest as well as intangible benefits that might be derived from a partnership between the LCS study team and their organization. Through this process, mutual needs could be met even with minimal financial resources.

Upon receiving the approved list of organizations to contact, RTI will work with the planning team to finalize contact materials (e.g., letters, study brochures) and procedures. We expect to utilize several different methods (e.g., phone, e-mail, letter) to contact these organizations, provide a description of the study and data collection plans, and ask for their support. In addition, we will determine the individuals in these organizations who are in the best position to serve as stakeholders for the established sampling areas and groups.

RTI will also begin to implement the agreed-upon community involvement strategy as community groups and stakeholders are brought on board. Activities might include working with the LCS planning team to design a study logo and other informational materials, creating and testing media messages, and coordinating community meetings and other activities.

Step 6: Identify Lessons Learned and Update Strategy

It will be important to identify lessons learned throughout the community involvement process and to update the strategy in order to maintain its effectiveness. The strategy may also need to be updated as community characteristics and composition change over the time period of the study. RTI recommends an interactive community involvement process designed to foster regular debriefings with community members, organizations, and stakeholders as a way to gather feedback in order to improve the community involvement process. We also believe these lessons learned will provide insight for the NCS in the form of transferable approaches that prove to be successful. RTI will work with the LCS planning team to identify the type and frequency of feedback mechanism and the desired participants, implement the approach, and disseminate results as necessary.

4.0 Conclusion

Community involvement will be a critical component both in this NC Cohort Study and in the future NCS. We have presented here a general framework, based on recognized principles, to begin to develop a community involvement strategy, as well as the steps needed to refine and implement the strategy for the NC Cohort. More detailed procedures will be developed as the study parameters and design aspects are further defined, and as the LCS planning team determines the nature of the community involvement necessary for this study.

4.0 References

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